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HEALTH CARE NEEDS OF PERSONS WITH SEVERE DISABILITIES

BY

© MADHAVAN THUPPAL

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND

RESEARCH IN PARTIAL FULFILLMENT OF THE REQUIREMENTS

FOR THE DEGREE OF MASTER OF EDUCATION

IN SPECIAL EDUCATION - SEVERE DISABILITIES

DEPARTMENT OF EDUCATIONAL PSYCHOLOGY

EDMONTON, ALBERTA

FALL, 1994

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Madhavan Thuppal
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R Sobsey

Dr. R. Sobsey, supervisor

D Baine

Dr. D. A. Baine

J Magill-Evans

Dr. J. Magill-Evans

Date: October, 5, 1994

DEDICATION

To my beloved brother
Dr. Tuppal Ramanuja Chari

ABSTRACT

Study of health care needs of persons with severe disabilities is important to plan their community placement. This study investigated the health care needs of 36 individuals with severe and multiple disabilities residing in a facility in Western Canada. Data was gathered on a format made for the study, from the medical records of the residents. The data included details on age, sex, duration of stay in an institutional setting, medical problems during the preceding three years, current medication, number of physician consultations during the past six years, and health care procedures in their daily care. Details on health and nursing care procedures were gathered with regard to seizure control, feeding, medication administration, mobility, handling and positioning, and routine care.

Results showed that the major health care concerns were management of seizures (77.7%), gastrointestinal problems (63.8%) including reflux and constipation, choking and aspiration (27.7%), prevention of skin breakdown (27.7%) and care of fractures (22.2%). All subjects were dependent on staff for feeding and other self-care activities. Ten (27.7%) were receiving feeding through gastrostomy tube. All subjects needed the use of wheel chairs for their mobility. Medication administration was a major health care activity. Analysis of the current prescriptions revealed that 97.2% were on laxatives, 88.8% on anticonvulsants, 58.3% on skin preparations, 30.5% on antipsychotics and hypnotics, and 27.7% on each of gastric motility drugs, bronchodilator drugs, and antacids. On an average, each client required 2.2 physician consultations per year during the past six years. The implications of these findings for moving the residents into the community are discussed.

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The data for the project was collected at a facility for persons with severe and multiple disabilities in Western Canada. In order to protect the identity of the center I am not in a position to name the facility. The manager, nursing staff, and aides were extremely helpful in giving me the records and making my stay in the center comfortable. I convey my sincere thanks to all the staff members at this facility. The research work would not have been possible without the consent of numerous parents and guardians. I thank all the parents and guardians for having consented to give access to the medical records of their wards.

Special thanks to Richard Lucardie, Wade Randall, Gill Rutherford, Sheila Mansell, Tansel Erdem, and Don Wells for their constant encouragement and making the life in the laboratory great fun.

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Chapter 1

Introduction and Overview

Persons with severe mental retardation and multiple disabilities constitute a highly heterogeneous group with different etiologies and symptoms. Formulating a simple definition for this group is not an easy task. The largest single characteristic among these people is, mental retardation (Van Etten, Arkel, & Van Etten, 1980). In many persons, mental retardation may not be the primary disabling condition, but they may have one or several secondary conditions like cerebral palsy, hearing disability or visual disability. Earlier definitions of severe disabilities were based on exclusion criteria. People who were nonambulatory, incapable of basic self-care, unable to communicate basic needs and wants, and manifested deviant, destructive or antisocial behavior were grouped together under the category of severe disabilities, in spite of vast individual differences. Brimer (1990) proposed a working definition of persons with severe disabilities as follows:

> Persons with severe disabilities have a very significant functional discrepancy in: (a) general developmental abilities, (b) caring and looking after themselves, (c) expressing thoughts, ideas, and feelings, (d) responding to environmental stimuli, and (e) interacting socially with chronological-age peers. (p. 14)

The advantage of such a definition is the emphasis on functionality. Individuals with severe disabilities are not identified on the basis of

nonfunctional developmental timetables, but rather by comparison of the skills they need in the environment, and the skills they have acquired. Such a change in the trend can be observed in the 1992 definition of mental retardation by the American Association on Mental Retardation (Luckasson, Coulter, Polloway, Reiss, Schalock, Snell, et al., 1992). In the 1992 system, mental retardation refers to

> substantial limitations in present functioning. It is characterized by significantly subaverage intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self direction, health and safety, functional academics, leisure, and work. Mental retardation manifests before age 18. (p. 5)

Diagnosis and classification in the 1992 system has a three-step process of (a) diagnosis, (b) description of individual strengths and weaknesses, and (c) identification of needed supports. The major implications of this system of definition and classification for the field of mental retardation were discussed by Schalock, Stark, Snell, Coulter, Polloway, Luckasson, et al. (1994). This definition falls in line with the definition of persons with severe and multiple disabilities given by Brimer (1990). For the purposes of this study, the definition as given by Brimer will be used.

The prevalence of severe mental retardation as estimated by Abramowicz and Richardson (1975) on a review of twenty-seven community

studies was 0.3 to 0.5 percent or one in 200 to 333. The prevalence varies from one study to the other based on the operational definition, setting and the type of instrumentation.

Causes of severe mental and physical disabilities are discussed at length in various sources, and these include genetic and chromosomal disorders, nutritional and metabolic disorders, infections and intoxications, cranio-facial anomalies, degenerative disorders, and environmental factors (MacFaul, 1986). However, one of the largest categories in any of the etiological studies is the 'unknown' group. While the study of the causes is important from the preventive perspective, a study of the characteristics of persons with severe disabilities helps in identification and management. Individuals with severe disabilities have problems in self-care, communication, mobility, cognitive abilities, social skills, and appropriate behavior. Because of varied amounts of damage to the neuromuscular and other systems, persons having severe disabilities have associated medical problems like seizures, gastrointestinal motility disorders, inadequate ventilation of lungs, renal and cardiac disorders, sensory deficits, and susceptibility to frequent infections (MacFaul, 1986). Smith (1984) in a review of the nature and needs of students with severe and profound handicaps, inferred that interpretation of this medicine data for each individual is necessary for proper instructional planning. Persons with mental retardation, in general, have unique health care needs posing a significant challenge to the health care delivery system. With the principle of normalization and consequent deinstitutionalization movement of the 1970s,

many individuals with mental retardation have been moving from large institutional settings to smaller community-based living accommodations. Accordingly, their dependence on generic services, including community health care has increased. The range of health care delivery services needed by persons with mental retardation in the community include: (a) an identifiable primary care provider capable of overseeing the medical care of individuals with mental retardation, possessing specific knowledge and expertise of the unique medical and social needs of this population; (b) linkage with medical subspecialists experienced in working with this population; (c) mental health and behavioral services; (d) genetic services; (e) rehabilitative services, including speech, occupational and physical therapy; (f) dental services; and (g) health care coordination (Crocker & Yankauer, 1987).

Though the deinstitutionalization movement resulted in community life for many persons with mental retardation, many of those labelled severely and profoundly retarded still remain in public or private institutions (Eyman & Borthwick, 1980). With increased activism by advocacy groups, philosophical perspectives supporting use of community residential settings, and decreased mortality rates for people who are severely and profoundly mentally retarded, it is expected that a greater number of these individuals will slowly move to community, residential placements. As persons with severe handicaps have many chronic health problems needing continual supervision, review of the health care needs and patterns of their service

delivery will help in successful community placement. With this end in view, a study was undertaken to examine the health care needs of a group of persons with severe disabilities in an institutional setting.

Chapter 2

Review of Literature

A historical survey of the services for persons with severe disabilities reveals a field that is dynamic and evolving. The past decade has seen an expansion of the services; growing public awareness of and concern over the person with disabilities rights, access, and treatment, parental demands for educational and therapeutic services; advances in training of professionals who treat and serve persons with severe disabilities; and court, and statutory mandates for more appropriate and adequate services (Brimer, 1990). In spite of such a massive thrust for community placement, many of these individuals still live in institutional settings. One major reason for placements in large residential settings is the continuous health care needs of these individuals and their need for the presence of adequate nursing and support staff for day to day activities. A review of literature on health care needs of persons with severe disabilities shows that the researchers approached the problem from different perspectives such as prevalence of different needs; survey of teachers, parents, and physicians; and specific health care needs.

Prevalence studies:

Hayden and DePaepe (1991) reviewed the medical conditions, level of care needs and health-related outcomes of persons with mental retardation. The authors reviewed 47 studies in relation to persons living in institutional settings as well as in the community. The overall data indicated that

individuals with similar medical conditions resided in community as well as institutional settings. However, some studies indicated that those living in institutions had higher prevalence of specific health problems. An analysis of health care needs showed that the level of medical care needed was comparable in persons living in communities and institutions. Several studies in the review by Hayden and DePaepe indicated that persons with intensive medical complications lived in a variety of residence types. The studies reviewed by the authors, did not have a common denominator on which they could be compared in specific areas in order to draw specific conclusions. The authors asserted that the delivery of health care to persons with severe retardation is more a medical than a residential issue.

In a study of client characteristics and residential placement patterns, Borthwick, Eyman, and White (1987) examined the patterns of placements of 66,367 clients receiving services for mental retardation in the state of California. The subjects were living in institutions, community care programs, health facilities, or with parents or relatives. The data on the clients were gathered from the client development evaluation reports, completed by direct-care staff or social workers. On a discriminant analysis of the data, three groups of persons were identified: those with maladaptive behavior, those with adaptive behavior deficits and those with major medical conditions. Age and ethnicity emerged as factors in the third group, along with medical conditions. Maladaptive behavior and major medical problems were evident in institutional clients, while the nonambulatory clients tended to cluster in

health facilities. Health care facilities and institutions cared for the lowest functioning clients, having the fewest skills. The final data suggested that those with serious behavior problems or medical needs tended to be in institutions because their problems were difficult to handle in the community settings. The authors also inferred that it was not just client characteristics that determined the placement process. Care provider preferences, lack of services or other barriers associated with the surrounding community, and availability of placements and subjective judgments by service system professionals also affected placement decisions.

A report on the functional and health status characteristics of persons with severe handicaps in New York state (Jacobson & Janicki, 1985) presented findings on the characteristics of children and adults living in institutional and community settings. The data was based on a statewide survey by the New York State Office of Mental Retardation and Developmental Disabilities from 1978 to 1984. While the total population receiving services for developmental disabilities was 76,500, the report was based on a subset of 22,256 persons. The results of the study showed that persons with profound mental retardation living in the community were younger, had a higher reported rate of cerebral palsy, had a lower overall rate of chronic physical impairments, and fewer reported problem behaviors. A sub-group of persons with profound retardation (34%) were classified as frail retarded persons. These individuals had a variety of physical conditions, sensory impairments, profound cognitive

deficits, a lack of mobility and a deficit of adaptive skills. Because of their varied needs, their maintenance costs were high. All frail individuals received basic medical care and most received needed nursing, routine health care, and psychological services. Higher service levels were apparent for children in institutions as compared to those in the community. A conclusion of this study, among others, was that persons in institutions did not differ markedly from those in the community. The authors further concluded that many individuals with severe disabilities, who did not require intensive, institutionally-based services were still waiting return to the community.

Survey of teachers:

With more people with severe handicaps participating in regular school programs, there is a greater need to implement health-related procedures in class rooms. In a questionnaire survey of 150 teachers of students with severe and multiple impairments, Ault, Guess, Struth, and Thompson (1988) observed that teachers were indeed involved in providing health-related procedures for students in classrooms. The teachers assumed more of this responsibility than did school nurses, or paraprofessional. Most of the teachers had training in implementing health related procedures on the job. While the focus of the study was more to develop policies on who should administer these health care procedures, and determine appropriate types of training for teachers, it could be inferred from the study that persons with profound and multiple disabilities can be managed in regular classrooms if their teachers receive appropriate training for student management. Two of the many health care

needs addressed by teachers of students with profound disabilities included medication administration, and nutrition monitoring and supplementation. The most common medication was for seizures (76% to 88%). Almost all (98%) of the students required some form of assistance during meal time, the majority required full feeding assistance from care giver; 17% receiving nutrients through a gastrostomy tube (Ault, Guy, Rues, Noto, & Guess, 1994). Typical mealtime problems included difficulty chewing, sucking, and swallowing. Chronic constipation, choking, gagging, and aspiration were identified as concerns.

While it is known that the level of health care needs in persons with mental retardation in institutions does not significantly differ from those in the community (Hayden & DePaepe, 1991; Jacobson & Janicki, 1985), family members tend to feel that persons in institutions need greater amounts of medical care. Such attitudes on the part of family members can result in families challenging the deinstitutionalization policies. Investigating the perceptions of families and staff members on the medical needs of persons with mental retardation in institutions, Conroy (1985) analyzed the responses of 415 family members and the staff members of an institution. The results showed a gross discrepancy between the two sources, with the families perceiving the need for much more intense medical care among the residents of the institution.

Survey of parents and physicians:

Investigating the concerns of parents of children with moderate and severe mental retardation, Chomicki and Wilgosh (1992) observed that severity of intellectual impairment was an important determinant of the number and nature of concerns experienced by parents, when seeking health care services for their children. On an analysis of the responses of 51 parents/ caretakers to a questionaire survey, the authors found that parents of children with severe mental retardation indicated that they perceived a difference in the nature of health care services that were provided to their disabled and nondisabled children. While receiving appropriate health care is the concern of parents, providing health care to persons with disabilities presents special challenges to physicians, especially those in community-based practice. Minihan, Dean, and Lyons (1993) in a survey of 342 physicians from various specialties (40% were from family practice and internal medicine) observed that inadequacy of medical information was the greatest obstacle to physicians' efforts to manage the care of patients with mental retardation living in the community. Cognitive and verbal limitations, difficulty communicating with multiple care givers and maladaptive behavior of patients in the physician's office were listed as moderate or minor problems. Only 20% of the physicians described themselves as well prepared to cope with uncooperative patients. The measures suggested to facilitate the clinical management of patients with mental retardation were preparation of: a list of

physicians in many specialties who are experienced in the field of mental retardation, referral guide to physical and occupational therapy, and a pamphlet describing state policies concerning informed consent for medical treatment of persons with mental retardation. The physicians generally felt that continuing education programs were less useful.

In a study on whether the medical needs of persons with mental retardation were met, Howells (1986) observed that persons with mental retardation did not place a greater burden on general practitioners than did patients from the general population. The author studied the nature of medical problems in 151 persons in an adult training centre. It was found that a large number of common medical problems of persons with mental retardation were unmanaged (203 out of a total of 279, or 72.7%). Lack of adequate medical care resulted in a poor quality of life for the trainees. Many trainees were cared for by their aging relatives. The relatives often felt that the complaints of persons with mental retardation were often trivial in comparison to the major handicaps which were untreatable. The general practitioners were limited by a lack of information on the organization of local services for persons with handicap. Similar trends were observed by Wilson and Haire (1990) in a study of health care for people with mental handicap living in the community. Their subjects did not consult a general practitioner more frequently than did people in the general population, but were more likely to be taking prescribed drugs. Fifty-seven percent of their prescriptions had not been reviewed by a doctor. Howells (1991) suggested the introduction of special postgraduate

training for physicians to ensure that satisfactory standards of health care were achieved for persons with disabilities living in the community.

Studying the general characteristics of persons with severe mental retardation and multiple disabilities, Thuppal and Narayan (1990) reported that seizures, physical handicaps, sensory handicaps, and hyperactivity were the most common associated problems. The authors studied a group of 164 persons, mostly in the younger age group (less than 25 years), with profound mental retardation. They formed 22% of the total attendance in a day care facility for persons with mental retardation. The services needed by these persons were training in self-care skills, training in communication, medication for seizures, physiotherapy, and management of problem behaviors.

Adults with mental retardation:

With the increase in the quality of health care, the life expectancy of persons with mental retardation has increased. Accordingly there is a focus on the health-care needs of adults with mental retardation (Rubin, 1987; Seltzer, Finaly, & Howell, 1988). Reviewing the health care needs of adults with mental retardation who lived in a large state residential facility, Nelson and Crocker (1978) concluded that there were multiple issues and a need for an integrated program. They found that 56% of the population had behavioral disorders; 34%, seizures; 33%, cerebral palsy; 24%, hearing loss; 13%, respiratory disease; and 10%, visual handicap. Discussing the health care needs of adults with mental retardation, Rubin (1987) identified four major

areas of concern for the group with severe physical handicaps. These concerns were seizure disorders, multiple joint contractures, feeding difficulties with need for feeding tubes, recurrent gastro-esophageal reflux, and recurrent respiratory problems. In a study of the functional characteristics of elderly persons with mental retardation in community settings and nursing homes, Seltzer, Finaly, and Howell (1988) compared people living in community-based settings with those in nursing homes, with respect to medical status, and behavior problems, in addition to formal and informal supports. Based on a 'goodness of fit' hypothesis, the authors expected that functionally impaired individuals would live in more restrictive environments. Contrary to their hypothesis, the authors found that nursing home residents had fewer behavior problems and fewer medical problems than did the persons living in community-based settings.

In a longitudinal participant-observation study of 17 people with mental retardation, with a mean age of 65, living independently, Edgerton, Gaston, Kelly, and Ward (1994) compared the sample with a group of 30 individuals of comparable age living either in parental homes or community residential facilities. Both groups had poor health maintenance practices, and almost all had difficulty communicating with health-care providers. People who lived in community residential facilities or relatives' homes usually had adequate health care provided for them, while those living more independently had difficulty accessing health care.

In a review of the mental and physical health, and ageing in mental

handicap, Day and Jancar (1994) noted that mental and physical health problems in elderly persons with mental handicap are similar to those of the elderly population as a whole, except for a higher frequency of behavior disorders. Special problems observed in persons with Down syndrome were premature senility and dementia. The physical problems of elderly persons with mental retardation were comparable to those people in general population, of matching age. The authors expected higher health related problems in people with mental handicap. Since there was a higher mortality and morbidity in people with severe handicap (differential mortality) after age of 50 years, no differences were observed.

Gastrointestinal problems:

Some of the specific health care concerns, apart from seizures and respiratory problems, are poor gastro-intestinal motility, reflux of food; accidents and falls leading to fractures; and gynecological problems. In a retrospective study of hospital records, over a 50 year period, Jancar and Speller (1994) observed that persons with mental retardation had a higher prevalence of chronic constipation and megacolon. These conditions predispose the individuals to fatal intestinal obstructions which may present late, and with deceptively minimal signs. The study revealed that there was a higher incidence and lower mean age at death of fatal intestinal obstruction compared with the incidence among the general population. Intestinal volvulus was a common cause of obstruction. The risk is higher among those

individuals with restricted mobility. Chronic regurgitation is a major problem in persons with severe mental retardation. The prevalence of recurrent vomiting was found to be 10% in institutionalized adults with mental retardation (Kuruvilla & Trewby, 1989). In a survey of institutionalized adults with severe disabilities, Rogers, Stratton, Victor, Kennedy, and Andres (1992) observed that 23 of the 220 residents had chronic regurgitation, with or without emesis. All of these adults were investigated in a feeding disorders clinic. Twenty-two of the adults had gastroesophageal abnormalities. The authors of this study recommend a thorough investigation with esophagograms and gastric emptying studies of all adults with severe mental retardation presenting with emesis or reflux.

Injuries and fractures:

Client injuries pose serious problems in program continuity, minimize benefits of excellent training programs, and cause administrative and economic problems. In a study of patterns of injury in institutionalized mentally retarded residents, Spreat and Baker-Potts (1983) analyzed the data from the injury report forms of 140 persons with mental retardation, in a residential setting. The results indicated that cohorts with moderate and profound retardation appeared to be most injury prone. Persons with mild and moderate mental retardation had restraint related injuries. Persons in the severe group seemed to be the victims of institutional environments while the injury pattern in profound group seemed to be congruent with their typically diminished physical capacities. Jancar (1989) on a review of the files of 731

residents with mental retardation, aged 40 years and above, from four hospitals in Bristol, noticed that 117 persons (16%) sustained one or more fractures (182 fractures). The cause of fractures in 67 instances was unknown, while in 74 instances, it was due to falls. The other causes for fractures were seizures, fights with fellow residents and car accidents. The most common fracture sites were femur, hand, ankle, foot, and clavicle. Fractures due to unknown cause occurred in persons with more severe handicaps. Osteoporosis, osteogenesis imperfecta, bone dysplasias, epilepsy, and use of psychotropic drugs (producing giddiness and falls) were identified as possible predisposing factors for fractures in persons with severe disabilities. Dunne, Asher, and Rivara (1993) used the data from the 1988 National Health Interview Survey to compare the injury rates among community-based young people with developmental disabilities, young people with chronic illness, and normal controls. The results indicated that children with disabilities had higher injury rates than did controls, while children with chronic illnesses tended to have lower rates of injury as compared to their controls. Sex differences in injury rates were not the same for children with and without developmental disabilities. Female children of all age groups in the controls had far less injuries than did either the developmental disabilities group or the chronic illness group.

Gynecological problems:

One of the health care concerns often not addressed, but of importance

is gynecological problems in women with developmental disabilities. These problems range from attention to menstrual hygiene and contraception to seeking help during periods of dysmenorrhoea (painful periods). Huovinen (1993) conducted a case control study on the gynecological problems of women with mental retardation in Finland. Two hundred and fifty-five women with mental retardation, requiring gynecological assistance, were compared with age matched normal women. Women with mental retardation did not give birth to children; had far fewer pregnancies, legal abortions, gynecological laparotomies, and diagnostic curettage. Lynestrenol, a progesterone preparation, was administered to a large number of women with mental retardation to induce therapeutic amenorrhea (cessation of menstrual periods). In addition, it was observed that women with mental retardation had greater age at menarche, small hymenal ring on pelvic examination, extremely small uterus, fewer genital infections, and fewer tumors of all kinds.

Medications:

Excessive use of pharmacological and anticonvulsant medications is another health-care concern which has been debated for more than two decades. Pharmacological agents are widely used for suppression of aberrant behavior. Use of these drugs is severely criticized. The prevalence of psychotropic drug use varies from 36.9% to 85.9% in institutional settings to 15.1% to 32.5% of clients in school-based settings. The use of anticonvulsant medication shows a similar trend (Aman & Singh, 1991; Baumeister, Todd, &

B evin, 1993; Zaharia & Struxness, 1991). The prevalence of psychotropic drug use in persons with mental retardation increases with age, irrespective of the type of environment in which the individuals live (Pary, 1993). However, Meins (1990) reported that the use of antipsychotic and anticonvulsant medication decreased in older persons with mental retardation, in the Federal Republic of Germany.

Harper and Wadsworth (1993) investigated the relationship between behavior problems and medication utilization in persons with mental retardation. The authors examined the medical records of 87 adults from congregate care environments and group care environments. Forty-nine percent of Harper and Wadsworth's sample were receiving psychoactive medication at the time of the study. Sixty percent of those receiving the drugs, had received them continuously for five years or more. More residents from larger congregate settings received psychotropics as compared to individuals from small, group homes. Psychotropic and anticonvulsant drugs tend to suppress behavior, in general. The drugs limit both undesirable and desirable behaviors, thus interfering with the acquisition of positive skills (Martin & Agran, 1985). Moreover, the drugs have many side-effects. In a study of neuroleptic-induced parkinsonian side-effects, in persons with mental handicap, Rao, Cowie, and Mathew (1989), observed that 85% of their subjects had mild disturbances, and 15% had moderate disturbance in movements. The involuntary movements were manifest more often in faces, hands and feet. In

a study of 55, long-term residents in a facility for persons with severe mental retardation, Gowdey, Coleman, and Crawford (1985) observed lens opacities and corneal changes in 14 persons. All the residents were receiving more than 100 mg per day of the phenothiazine group of medications. Their study indicated that short-term high doses of medication may have been more important than were long-term, low dose intake of phenothiazines in causing ocular side-effects. The use of hepatic-enzyme inducing drugs seemed to afford some protection against these side-effects.

Use of neuoleptics can result in precipitation of seizures in those with a history of this disorder. James (1986), in a retrospective study of 217 persons with mental retardation, observed that high dose neuroleptics precipitated seizures in those with a history of seizures. However, there was no increased risk of developing seizures amongst persons with mental handicaps receiving neuroleptic medication, if there was no past history of epilepsy.

Research studies in mental retardation, in general, under-reported medication information of the subjects (Agran, Moore, & Martin, 1988). Psychoactive drug use seems to increase with increases in age of persons with mental retardation. Except in instances of severe, self-injurious behavior, a therapeutic rationale for use of psychotropic drugs does not seem to exist. In a review of psychopharmacology of self-injurious behavior, Farber (1987), discussed the relationship between the use of behavior modification techniques and pharmacotherapy. While it is recommended that one should refrain from using psychotropics with persons having problem behavior, one

has to be careful in withdrawing the medication in cases of self-injurious behavior. Drugs like naltrexone, which are opiate antagonists, have been shown to be effective in reducing self-injurious behaviors in some persons with severe mental retardation and autism (Zingarelli, Ellman, Hom, Wymore, Heidorn, & Chicz-DeMet, 1992). However, consistent results need to be reported before one can routinely prescribe this medication in severe self-injurious behavior. Pharmacological agents may have potential use in established instances of mental illness in mental retardation. One may have to consider the adverse effects of psychotropic medication in terms of involuntary movements, refusal to cooperate in feeding, as well as giddiness and falls in persons with severe disabilities. As rightly noted by Bishop (1992), there is no conceptual model of psychopharmacology for individuals with severe or profound mental retardation. A six phase psychopharmacologcal, data-based, decision-making model was proposed by him. The phases were, (a) careful description and analysis of target behavior, (b) behavioral intervention, (c) initial psychopharmacologic phase, (d) stabilization phase in which drugs as well as behavior program are adjusted, (e) psycho-pharmacology taper phase, and (f) post-psychopharmacologic assessment phase.

Desirable and expected behavioral changes were observed in the combined use of behavioral modification techniques and psychotropic drugs in a group of 22 community-based persons with mental retardation (Schalock, Foley, Toulouse, & Stark, 1985). Clinical pharmacological issues in treating

problem behavior in persons with mental retardation, were discussed under six major categories by Arnold (1993). The categories were, target disorders, substrate for drug interaction, dosage sensitivity, choice of medication, statistical complications of clinical import and ecobehavioral considerations.

Seizures:

Seizures are reported as the most prevalent secondary chronic health problem in persons with mental retardation (Taylor, 1985). In an epidemiological study of children with mental retardation in London, Corbett (1974), found that 32% had a history of epilepsy at some time during life while 19% had at least one seizure during the previous year. The prevalence of epilepsy increases with increases in the severity of mental retardation (O'Donohoe, 1994). Presence of seizures tends to increase problem behaviors of persons with mental retardation (Lechtenberg, 1985). Anticonvulsant medications are hence prescribed on a long-term basis to control seizures in persons with mental retardation and seizures. While it is necessary to control the seizures, one has to be aware of the side-effects of the anticonvulsant medication. In a study of 312 children with complicated epilepsy attending a special hospital school, Corbett, Trimble, and Nichol (1985) observed significant association between long-term anticonvulsant therapy with phenytoin and phenobarbitone, and cognitive deterioration. There was no association between anticonvulsant medication and overall behavioral deviance. Specific behavioral disturbances were associated with focal cerebral dysfunction. Use of multiple anticonvulsant drugs seemed to

complicate the problems. A shift towards monotherapy, and a change to sodium valproate and carbamazepine as first-line drugs was recommended, with careful monitoring of anticonvulsant blood levels in order to achieve optimal results.

In addition to psychotropic and anticonvulsant medications, drugs are prescribed for physical conditions in persons with mental retardation. In a one day survey of the prescriptions for physical complaints in two hospitals for persons with mental handicap, Searle, Berelowitz, and Wright (1989) observed 36% to 43% of the residents received medications. The usage of drugs increased with increasing age. The categories of frequently used medications were: gastrointestinal drugs in 13% of patients, vitamins and nutritional supplements in 11%, dermatological preparations in 10% and cardiovascular drugs in 10%. Drug usage increased with the increase in severity of mental retardation.

Health care issues and procedures affect the quality of life of persons with profound disabilities. There could be yet unidentified factors within the health care system that can have a profound effect on their lives (Sulkes, 1991). Qualitative issues such as the skill and experience of the health care providers, health care coordination of preventive care, and adequate staff training can help in increasing the life expectancy of persons with mental retardation (Kastner, Nathanson, & Friedman, 1993). Presence of some health care problems like lack of feeding skills and mobility were used in studies of

life expectancy estimates of persons with mental retardation (Eyman, Call, & White, 1991). Thus, health care issues and procedures form a vital part of the care, management and training of persons with severe disabilities.

Summary:

The studies reviewed indicate a higher prevalence of medical problems in people with severe disabilities. Persons with severe disabilities are often restricted to institutional settings because of the presence of associated medical conditions, barriers to providing adequate services in the community, and concern of parents, professionals, and administrators that the health care needs may not be adequately met in the community. However, with the deinstitutionalization movement gaining momentum, only adults with severe disabilities tend to continue to live in large institutions while younger individuals tend to stay in the community. Recent studies show that people with severe disabilities, placed in institutions, do not differ markedly from individuals living in the community, and individuals with severe disabilities can be managed in regular classrooms providing that teachers are trained in medication administration, and nutrition supplementation.

The literature suggests that the most common medical problems faced by persons caring for people with severe handicaps are: seizure control and monitoring; administration of medication for seizures and severe behavior problems; meal time concerns like problems in chewing, sucking, and swallowing; gagging, choking, reflux of food and aspiration; chronic constipation; attention to self-care skills including toiletting; and mobility.

Physician care of people with disabilities in the community-care system can be improved by providing physicians with adequate information on management of people with cognitive deficits, verbal limitation, and maladaptive behaviors. With the increase in the life expectancy of people with severe disabilities, one has to focus on adults and aging in this group, medical emergencies like fractures and acute abdomen, and gynecological problems. Earlier recognition of these individuals and prompt management will go a long way in enhancing their quality of life. The physicians need to adhere to the current trend in the reduction of medication, particularly for seizures and problem behavior of people with disabilities. Integration of pharmacological and behavioral intervention can achieve optimal results in their management.

Placement in the community, reduction of medication, and normalizing their activities may enhance the quality of life of people with severe disabilities. However, the move to place a group of long-term residents of an institution needs careful planning after appropriate assessment of their requirements both in terms of the type of accommodation, and fulfilment of nursing and medical needs. Each person has to be individually evaluated for specific needs. Availability of appropriate health care providers in community settings needs to be ensured. Literature on health care needs of persons with severe mental retardation reviewed so far is derived from the studies conducted in the United States of America, Europe, and Australia. Studies examining the health care needs of persons with severe disabilities are

not available in the Canadian literature. Further, there was a need to have baseline information on the health care needs of a group of residents living in an institution. Hence, this research project aimed at assessing the health care needs of a group of individuals in a facility for persons with severe and multiple disabilities was conducted.

Chapter 3

Materials and Methods

The purpose of the study was to describe the health care needs in a group of individuals with severe and multiple disabilities. The data was gathered to list the number and type of health care procedures required by individuals with severe disabilities, in order to study the feasibility of a proposed move to a community setting. Data was gathered on a format made for the purpose of the study. Items were included in the format based on the review of literature. The data was analysed to construct a profile of the needs of people with severe disabilities.

The method of data collection was from the medical case records of the clients. Data for this type of qualitative study could be collected by direct examination and observation of the clients, or interview with the care providers. But examination and observation of the clients to collect data would disturb the daily routine of the clients. Collection of data from case files or records is an accepted procedure of document study. For example data on persons with developmental disabilities were collected from varied sources like case files (Jancar & Speller, 1994), National health interview surveys (Dunne, Asher, & Rivara, 1993), client evaluation reports (Borthwick, Eyman, & White, 1987), and data base of the demographic and health status of persons in a particular state (Jacobson & Janicki, 1985).

The present facility was started in the early seventies with the transfer of number of residents from a large residential facility. As it generally

happens with facilities with chronic long stay clients, certain procedures are followed routinely without changing with the contemporary methods. A review of files by a person not routinely dealing with them can help identify such practices, which for a person routinely using the files would look normal. Howells (1986) used the method of both looking into the records of persons with mental retardation as well as a physical examination to assess whether the medical needs of adults with mental retardation were really met. No medical records, other than brief notes written at the time of placement in the centers, were available in Howells's study. However, the minimal information did give valuable information on the background of an individual. Hence data on health care needs were collected from the medical records of a group of individuals residing in a facility.

Description of the Centre:

The material for the study was collected from the medical records of one of the residential facilities for people with severe and multiple disabilities in Western Canada. This facility was started in the 1970s by the provincial department of family and social services. Most of the residents were aged less than 15 years when the centre was started. At the time of the study there were 64 residents.

The facility had a staff strength of about 90 including those in charge of house keeping. There were 54 direct service staff who are on duty in shifts, 25 persons worked during the day time, 21 in the afternoons and 8 during the

night shifts. In addition, many of the parents volunteered to work with the residents. There was one medical officer on roll. He was a pediatrician and he visited the facility twice a week. He was also consulted over the telephone in case of emergency, and sometimes he was on call duty. A dental surgeon visited the centre to carry-out the routine dental checkups of the residents. Nurse trainees, medical students, and practicum students from various disciplines attended the facility. Some parents visited the centre on a daily basis. The residents were housed on five floors of the building. There was an activity centre where the residents assembled in groups, at specified hours, for various types of stimulation activities. Generally, four of the residents shared a room, and each room was adequately equipped for routine needs of the residents. Suitable numbers of physical adaptive devices were available on each floor to take care of the mobility needs of the residents. Each person had a custom-made wheelchair. Beds had adequate railings to prevent falls. A group of residents attended a school program in the neighborhood. Many of the adults attended a vocational training centre.

Medical records:

Each resident in this facility had extensive medical records. Each record had a number of sections: general, nurses notes, doctors' prescriptions, doctors' notes, epileptic chart, annual conference notes, monthly summaries, catamenial (menstrual) charts, guardian details, physiotherapist notes, dental records, details of referrals, notes of the consultants, hospital reports of consultations and admissions, reports of investigations, any important letters

from parents and guardians, and legal papers related to consents and guardianship.

Initial pages in the records contained data on the date of admission, initial diagnosis, significant medical history, health care insurance details, and a summary of the latest status of the person, including the type of diet given, procedures for handling and positioning, and a brief description of daily routines. Nurses' notes contained important day-to-day activities like the presence of seizures, changes in medications, administration of PRN ('pro re nata', a latin word to indicate as the occasion arises) medication, and any illnesses. Doctors' prescriptions contained the medications for a period of three months. Doctors' notes consisted of details of annual examinations as well as the health status at each of the physician consultations. Dental records consisted of details of the annual, dental examinations and any procedures carried out like scaling or tooth extractions. The annual case conference reports contained the details of all the activities for the preceding year. The epileptic charts were maintained in two formats, one to note the individual attack and the other a cumulative monthly record. From these charts, total number of seizures were summed for each year under the subheadings of: grand mal, grand mal series, petit mal, petit mal series, Jacksonian and other.

Procedure:

A proposal was developed and submitted to the Research and Ethics committee of the Department of Educational Psychology of the University of

Alberta for ethical clearance. It was then submitted to the residential, treatment facility with a request to gain access to the medical records of the residents. The proposal was reviewed by the regional research and ethics review committee of the provincial department of family and social services. Letters to 64 parents/guardians were despatched on 22 April 1994 to obtain consent to access the records of the residents. The letters were mailed by the residential treatment facility to maintain confidentiality of the residents. Only 22 consent forms were obtained by the middle of June 1994. A follow up letter was sent on 16 June 1994, to those parents who still had not sent any reply. An additional 14 consents were obtained for the second letter. In all consent to access medical records of 36 residents of the facility were obtained. Two parents called to express their inability to give consent. They did not specify the reasons for not giving consent.

Data collection sheet:

The data was gathered on a format made for the purpose of the study. The construction of the format was based on the review of literature of types of health care needed by persons with severe and multiple disabilities. The data sheet had provision to record the following items: age, sex, duration of stay, significant history if available, details of medical examination and reports during the past 3 years, etiology, medical problems, medications currently administered, health related procedures in relation to seizures, teeth and gum care, skin care, feeding needs, bowel habits, respiratory system, handling and positioning, medication administration, shunt care, cast care,

prosthesis care, catheterization procedures, suction, oxygen administration, mechanical ventilation, tracheostomy tube care, colostomy care, gynecological problems, problem behavior, number of medical consultations, and any other significant item. In addition to basing the inclusion of items on the review of literature, concurrence was obtained from two professionals involved in the care and management of individuals with severe disabilities. Sample data collection sheet and the consent form are given in the appendix.

Data collection:

The data was collected at the facility. A list of residents for whom consent was available was prepared by the manager of the facility. Three records containing the medical and nursing information were handed over to the researcher each day. Details of clients were gathered predominantly from the intake summaries, annual case conference summaries, doctor's entries, current prescriptions, epileptic charts, and referral notes and reports from hospital consultations. The names of the residents were alphabetically coded. Doubts, regarding entries in the medical records, if any, were cleared by the nursing supervisors of the units. After initial collection of data from all the records, they were rechecked to ensure correct entry of prescriptions and physicians entries. The data from the sheets were tabulated manually and frequency counts and percentages were calculated for each of the items. Description of the various medications was gathered from the compendium of pharmaceuticals and specialties (Canadian Pharmaceutical Association, 1992).

Validity and reliability:

The present research is a descriptive study and hence specific hypotheses were not proposed. Further, this is a documentation analysis using a semi-structured schedule for collection of data. Qualitative research studies like interviews, participant observation, ethnographic studies, and document analysis may have observer bias (Fraenkel & Wallen, 1993). In the present study, entries were directly recorded from the reports. Every report in the records was scanned for presence of the specific problems. In addition, the nursing supervisors were consulted for clarification. This cross checking of data accounts for 'triangulation' effect in data collection, and it contributes towards of the validity of data. Serious questions on validity and reliability in qualitative research arise in interviews, and observation of a situation or event. To reduce observer bias and increase the validity of such studies, audio tapes and videotapes are used, in order to have a permanent product so that the researcher can go back to the record to recheck. In the present study, the documents reviewed were permanent records. At the end of collection of data from all the records, they were rechecked by the investigator and matched with the data collection sheets for any discrepancies. Rechecking data has the effect of establishing the validity and reliability. Moreover, the records are permanent at the facility and in case of disagreement by any person about the validity of the data, they can be rechecked to see whether appropriate data were collected.

Chapter 4

Results

A total of 36 medical records were reviewed. The overall response rate for parental/guardian's consent to review the files was 56.25% (36/64). The response rate for the first letter was 34.37% (22/64). Of the 36 clients, 20 were female and 16 were male. The age and sex distribution of the clients is given in Table 1. The majority of the clients were aged 21 and above. At present the

Table 1: Age & sex distribution

Age Group	Male	Female	Total
0-10 yrs	-	-	-
11-20 yrs	3	2	5
21-30 yrs	5	3	8
31-40 yrs	7	13	20
41 & above	1	2	3
Total	16	20	36

treatment centre caters to the needs of adults with severe disabilities. Many individuals were transferred as children from a different center 22 years ago.

The total duration of stay in the institution for each of the clients is reported at Table 2. It can be seen that 31 of the 36 individuals have stayed at the facility for more than 10 years. Only five of the 36 individuals were admitted during the past ten years. Twenty-two of the 36 residents (61%) have stayed at this center for more than 21 years. Some residents were transferred to the present facility after a period of stay at different centers or at home.

Table 2: Duration of stay of residents in institutional setting

No of yrs of stay	Present facility		Since birth*	
	M	F	M	F
0 - 5	1	2	-	-
6 -10	1	1	-	-
11-15	2	4	2	1
16-20	-	3	1	1
21-25	12	10	1	-
26 & above	-	-	12	18

* total duration of stay in a different facility and the present facility

The etiology of the condition is given in Table 3. In one third of the instances, the etiology is not known. The diagnostic category of cerebral palsy entered in the client records is not included as etiology, as cerebral palsy is a condition rather than a etiological category. Birth anoxia is the most frequent etiology. Degenerative disorders, encephalitis, and meningitis account for 20% of the etiologies.

The records had information on the medical needs of the individuals over the years. Since these records span a period of more than 20 years, in many cases, the medical problems requiring daily medical attention by a physician, admission to a hospital, referral for investigation, or referral for examination by a specialist during the past three years were gathered (Table 4). Four (11.1%) of the individuals did not have any reported medical

Table 3: Etiology of the condition

Etiology	N*	%
Birth hypoxia/asphyxia	7	19.4
Degenerative disease	4	11.1
Encephalitis	3	8.33
Hydrocephalus	2	5.55
Rubella	1	2.77
Schilder's disease	1	2.77
Prematurity	3	8.33
Prenatal injury	1	2.77
Meningitis	1	2.77
Tuberous sclerosis	2	5.55
Hemolytic disease of new born	1	2.77
Unknown	12	33.3

*The total number is more than 36 because a possibility of two diagnoses was present in two instances

Table 4: Medical problems during the past 3 years
(Requiring daily medical attention or hospitalization)

Age group	Sex	Nil	One	Two	Three	Four	Five	Six	Total	%
11-20	M	1	-	-	-	1	1	-	3	66
	F	1	-	-	1	-	-	-	2	50
21-30	M	-	-	-	2	2	1	-	5	100
	F	1	-	-	1	1	-	-	3	66
31-40	M	-	1	3	2	-	-	1	7	100
	F	-	2	5	3	1	2	-	13	100
41 &	M	1	-	-	-	-	-	-	1	-
above	F	-	-	-	2	-	-	-	2	100
Actual no.*		-	3	16	33	20	20	6	98	-

* gives the total number of problems for all individuals during the past three years.

problems during the last three years. The rest of the individuals had from one to six medical needs. Twenty-one (58.3%) residents had three or more medical conditions needing hospitalization or continuous care for periods ranging from one week to one month. There were a total of 98 such instances in 31 individuals giving an average of slightly more than one medical condition per year, per person. The nature of the medical conditions needing referral or hospitalization are given at Table 5. Some persons had the same problem on

Table 5: Medical conditions needing referral or hospitalization

Problem	N	Problem	N
Gastro intestinal		Eye & ear	
Intestinal obstruction		Ear ache/ infection	4
due to volvulus	1	Eye infection	2
Hiatus hernia	5	Skeletal system	
GI bleeding	2	Falls and fractures	10
Vomiting/reflux	6	Osteoporosis	1
Gastrostomy	7	Joint dislocation	1
Endoscopy	2	Genito urinary	
Peritonitis	1	Retention of urine	1
Dental surgery	3	Bartholinitis	1
Respiratory		Ultrasound uterus	1
Flu	3	Urinary infection	5
Epistaxis	1	Hydrocele drainage	1
Aspiration/choking	5	Testicular problems	2
Cyanosis	2	Nervous system	
Upper resp. distress	6	Seizures	8
Pneumonia	2	Agitation	1
Skin		Sleep disturbance	1
Burn, abrasion, cut	3	Dystonia	1
Skin sloughing	4	Allergy/sepsis/infection	4

more than one occasion. These problems are counted as one for the purpose of tabulation. For example, one client needed repeated tapping of a recurrent and persistent hydrocele. This problem was recorded only as a single event. Fractures and falls, seizures, gastro-intestinal problems (gastrostomy and reflux) and aspiration seem to be the most common problems needing frequent medical attention.

At the time of admission to the facility, some clients had associated medical problems in addition to multiple disabilities. Some of them like infections were curable, while others like seizures persisted. Seizures were diagnosed in 34 (94.4%) clients. Of the 34, six were free from seizures at the time of collection of data. Of these six, four were on maintenance medication. Thus, 28 (77.7%) continued to have seizures. Five clients had visual handicap, four had bronchial asthma, two had dislocation of hips, and one, a diagnosis of hypoplastic lungs, on admission to the facility.

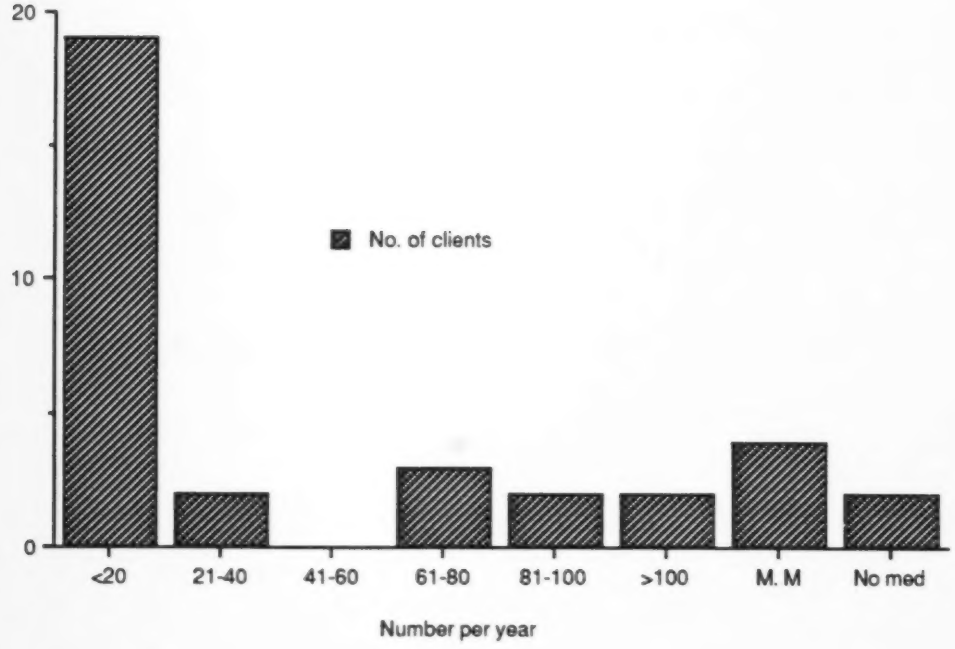
The number of seizures were recorded on a separate chart for each client. The total number of seizures during the period of a year, the nature of the seizure, type of first aid care given and the details of medication were recorded in the nurses' reports. However, the system followed in the facility does not seem to be in agreement with contemporary methods of classifying seizures. The seizure classification followed at the centre was: grand mal, grand mal series, petit mal, petit mal series, and Jacksonian. The records showed that most of the individuals had both grand mal and petit mal seizures.

There was no EEG documentation of absence seizures (petit mal) in any client. As it is uncommon to see both types of seizures (generalized tonic clonic and absence attacks) in an adult with mental retardation, two of the nurses and a nursing supervisor were informally asked on how they classified the seizure patterns. It was gathered that most of the grading was subjective. If the seizures were of short duration, without jerking movements of all limbs, and with minimal movements of hands or feet, they were classified as petit mal. Since this classification is not in keeping with the current practice of classification of seizure disorders (Aicardi, 1994), the data collected on different types of seizures was grouped under a single category while tabulating the data. Acceptable practice recommends that to arrive at the correct classification of a seizure, one has to witness and corroborate the nature of seizures with EEG findings. As people with severe disabilities are known to have diffuse cortical damage, the seizure focus would likely be in the cerebral cortex, and accordingly the type of seizures would be complex partial seizures. Hence, all the seizures in the present sample are counted as complex partial seizures. The frequency of seizures during the past three years in 34 clients are given at Table 6 and Figure 1. Of the 28 persons having seizures, three (10.7%) had exhibited status epilepticus during the recent three years. The health related needs requiring nursing care and their frequency are given in Table 7. The items listed are exclusive of the care required during seizures and hospitalization. The list also does not include the type of care. While routine dental care was given by the nurse or nurse's aid, specific

Table 6: Seizure frequency (N=34)

Number/year	No. of clients	%
Less than 20	19	55.9
20 - 40	2	5.9
41 - 60	-	---
61 - 80	3	8.8
81 -100	2	5.9
More than 100	2	5.9
Maintenance medication	4	11.7
No medication	2	5.9

Fig: 1 Seizure Frequency



M. M. = Maintenance medication

Table 7: Health related needs of clients

Health need	N	Health need	N
Dental problems		Respiratory	
Hypertrophy of gums	2	Bronchodilator nebulization	10
Tartar removal	1	Nasal spray	1
Scaling	3	Oxygen mask	1
Caries	1	Suctioning	3
Bleeding gums	1	Chest physiotherapy	3
Skin problems		Postural drainage	4
Wet due to drool	2	Cyanosis	2
Sore buttock	8	Choking	3
Rash	5	Aspiration	7
Skin breakdown	10	Fractures & dislocations	
Acne	2	Finger fracture	2
Callus	1	Ankle fracture	2
Dermatitis	1	Humerus fracture	2
Stoma site care	5	Fracture leg	1
Bruise rib/forehead	1	Fracture hip	1
Burn	1	Dislocation hip	2
Gastrointestinal		Others	
Gastrostomy tube care	10	Temp. monitoring	2
Reflux/emesis	2		
Diet type*		Physical/mobility	
Therapeutic nutrient	10	Wheelchair use	36
Nasogastric feeding	2	Scoliosis care	12
Regular diet	1	Kyphosis care	2
Minced diet	21	Care while crawling	1
Pureed diet	7	Helmet use	2
Gynecological		Care while scooting	1
Cramps	9	Use of walker	1
Heavy periods	2		
Irregular periods	2		

* Some clients were on more than one type of diet

dental care was required in only 8 instances over the past 10 years. All of the clients have an annual dental checkup by a dental surgeon. Skin problems in the form of breakdown were noted in 10 individuals. These individuals needed frequent change in positions. Sores over the gluteal region were noted in eight files. Gastrostomy tubes were present in 10 (27.7%) individuals. Fifty percent of the individuals needed constant care of the skin at the site of insertion of gastrostomy tube. Two persons had constant emesis which needed the attention of the care givers.

The diet required by the clients varied from therapeutic diet given through gastrostomy tube to regular diet. Only one person was given a regular diet while 21 had either a medium or a large minced diet. Seven were on pureed diets. Some persons were given more than one diet based on their condition during a given period. Two persons occasionally needed nasogastric feeds. Nasogastric and gastrostomy feeding were administered only by trained nurses, while the rest of the diets were given by the nurse aides. Menstrual cramps on a regular basis were present in nine clients. The conditions required administration of analgesics based on the intensity of symptoms. Regular catamenial (menstrual) records were maintained by the nursing staff. Urinary tract infections were recorded in five clients during the past three years. Two clients had testicular problems. One client had recurrent hydrocele which was aspirated 49 times and ultimately he had an orchiectomy (removal of testicle). Respiratory problems were noticed in ten clients. These

clients needed nebulization with brochodilators. Some needed these treatments four to five times a day. Some treatments were administered as and when required (pro re nata: p. r. n. basis). Three clients needed chest physiotherapy, four postural drainage and seven had recurrent aspiration problems which needed care during and after the feeding. Fractures and dislocations were present in ten persons. One person fractured his legs repeatedly. The etiology of the fractures is not known. Of the two hip dislocations, one was a case of congenital dislocation, while the other was acquired due to extreme contractures.

All the clients needed wheelchairs for mobility. One client could crawl and one could scoot. The individuals needed helmets when left on the floor to move around themselves. However, during such activities, they needed to be under the care of a nurse, aid, parent, or a guardian. One person could use a walker for brief periods of time. All of the individuals needed either a mechanical lift using the 'Medilift' or a two person lift for shifting between wheelchair and bed.

The personnel needed for carrying out the various health related procedures are reported in Table 8. There was no strict delineation of professional roles for some procedures like oral feeding or care during seizures. Any of the staff, nurse, nurse's aid, or the unit supervisor carried out the needed procedure. Sometimes parents or guardians helped in oral feeding of the clients. For procedures like gastrostomy feeding, suctioning in case of aspirations, qualified staff like nurses or nursing supervisors were

Table 8: Health related procedures and personnel needed by the clients

Procedure	Personnel
Seizure monitoring	Supervisor/Nurse/Nurse-aid
Teeth and gum care	Supervisor/Nurse/Nurse-aid
Skin care (bathing, changing positions)	Nurse-aid
Gastrostomy feeding	Nurse
Nasogastric feeding	Nurse
Bowel care (suppositories, fleet enema)	Nurse-aid
Diet monitoring	Nurse-aid
Postural drainage	Nurse-aid
Suctioning in case of aspiration	Nurse
Chest physiotherapy	Physiotherapist
Use of wheel chair, transfers, positioning	Nurse-aid
Transfers in case of fractures	Nurse
Cardiopulmonary resuscitation*	Any trained person
Medication administration	Nurse
Prosthesis care	Nurse/physiotherapist
Catheterization	Nurse
Oxygen supplementation	Nurse
Oxygen mask	Nurse
Gynecological problems	Nurse/Nurse-aid
Problem behavior	Nurse-aid/Nurse/Supervisor/ Other people present

*Not administered to those with 'do not resuscitate' orders.

required. So far as cardiopulmonary resuscitation (CPR) was concerned, it was not to be followed in 28 instances because of the do not resuscitate order (D. N. R.) policy followed at the centre. For reasons which are not clear, the physician of this centre mailed letters to the parents and guardians of the residents, asking their consent for a D. N. R. order for the clients in case of a life threatening event needing cardiopulmonary resuscitation. The D. N. R. however, does not include emergency medication, intravenous fluid

administration or assisted ventilation. Twenty eight parents and guardians consented for a D. N. R. policy with respect to their wards. The records do not show any instance of the clients having had a cardiopulmonary resuscitation. C. P. R. is listed in the table because it is a potential need, because many of the clients have conditions like seizures and aspiration which might end in a situation needing C. P. R. Many persons in the centre are trained in C. P. R. and they are eligible to administer the procedure.

One of the major problems encountered in people with severe disabilities is maladaptive behavior. The problem behaviors recorded in the case files are given in Table 9. The total number of clients who had behavior problems needing attention of the staff members was 22 (61%). Many persons had more than one problem listed in Table 10. Details as to the frequency and duration of the problem behavior in each person were not available. Self injurious behavior was observed in 13 individuals. This behavior includes head banging and biting self. Entries about the behavior problems were not

Table 9: Problem behavior

Behavior	No.
Restless	4
Violent	3
Self-injurious behavior	13
Fussy	1
Eats non-edibles	2
Rocking	1
Destructive	3

seen routinely in the records except in those with severe self-injurious behaviors needing physical restraint to prevent access to the part injured. An analysis of the types of medications prescribed for the clients is reported at Table 10. The details of the medications were collected from the most recent of the prescriptions. All persons were given supplemental vitamins. Thirty-five were given stool softeners or laxatives. The number of laxatives prescribed depended on the amount of intestinal motility problem. Some individuals with chronic constipation, were on a laxative/bowel routine. The general pattern of a laxative routine was administration of a laxative on the 3rd, and 4th, day

Table 10: Types of medications used

Medication category	No of clients	%
Vitamins	36	100
Laxatives/stool softeners	35	97.2
Anticonvulsants	32	88.8
Skin creams/lotions/ointments	21	58.3
Antipsychotics or hypnotics	11	30.5
Analgesic-antipyretic	11	30.5
Bronchodilator/antiasthmatic	10	27.7
Enteric feeding	10	27.7
Antacid/gastric mucosa protectants	10	27.7
Gastric motility drugs	10	27.7
Iron/calcium	7	19.4
Saline drops/moisturizers	5	13.8
Ophthalmic ointments/drops	4	11.1
Oral contraceptives	2	5.5
Antispasmodic	1	2.7
Others	4	11.1

of constipation, followed by suppositories on the 5th, and 6th, days of constipation. If the constipation was not relieved by the 7th, day, a fleet enema was given. All these medications were prescribed on a p. r. n. (as needed) basis. Of the 35 clients, twenty-one had three or more laxatives and stool softeners prescribed at the time of collection of the data.

Analysis of the regular prescription medication showed that the largest number of individuals were on anticonvulsants. Of the 32 on anticonvulsant medications, four were free from seizures and were on a maintenance dosage. Seven were on three anticonvulsants, fourteen on two and eleven on one. The details on the number of anticonvulsants and laxatives are given at Table 11.

Dermatological preparations in the form of skin creams and lotions were prescribed frequently because, restricted mobility predisposed the clients to skin problems. Moreover, ten clients with gastrostomy tubes had to have the stomal site kept free of infections. Antipsychotic medications were given in a minimal dosage. Three had an antipsychotic and a hypnotic combined. Bronchodilators were used in 27.7% of clients. All bronchodilator

Table 11: Frequency of prescription

No of drugs	Anticonvulsants	Laxatives
1	11	9
2	14	5
3	7	17
4	--	3
5	--	1

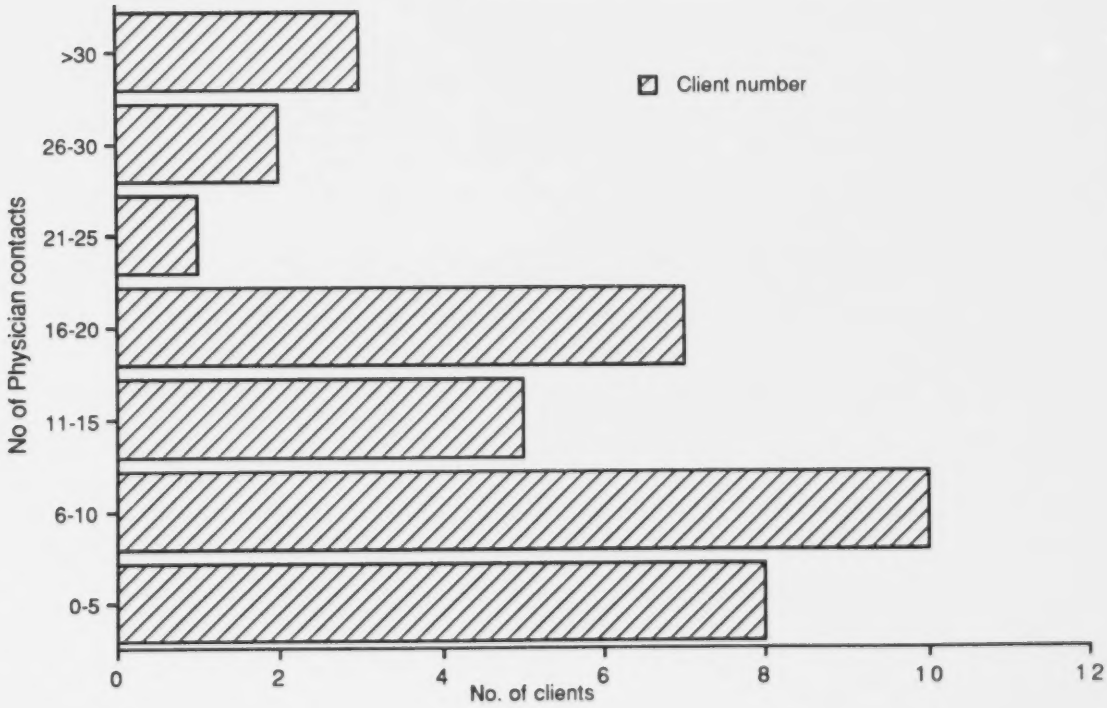
medications were given by nebulization, either at routine intervals or based on presence of respiratory difficulty. Analgesics and antipyretics were prescribed for 11 clients. Antacid preparations and gastric motility drugs were prescribed for 10 clients. Some persons had both antacids and gastric motility drugs prescribed, while some had only one depending on the presence of ulcer or reflux, reduced motility or both. The total number of medications on the prescriptions ranged from 4 to 14. Six clients had 4-6 medicines, 17 had 7-9 medicines, 12 had 10-12 medicines and one had 14 medicines. In those with large number of prescription drugs, the bowel routine itself contributed to four to five medicines.

The number of physicians' entries on the medical records gave an indication of the number of times the client required consultation with a physician. Every client had a annual medical check up. The details were recorded in the doctor's notes. In addition, as and when a resident needed a consultation, it was made available. These were consultations for either referral or management at the centre. The number of entries in the doctor's records for medical problems, as well as the annual checkup are reported in Table 12 and Figure 2. Twenty-three persons had less than 15 consultations since 1988. The total number of physician entries for all the clients were pooled from 1988 to the date of collection of data. A total of 522 physician entries were present for 36 clients over a period of 6.5 years. On an average this amounts to 2.2 consultations per client per year. The number of persons

Table 12: Entries in the Medical record since 1988

Medical Problems	N
0- 5	8
6-10	10
11-15	5
16-20	7
21-25	1
26-30	2
> 30	3

Fig : 2 Number of Physician contacts since 1988



needing more than 15 consultations since 1988 was 13. Three clients needed more than 30 consultations since 1988. All the residents had regular, annual medical examination. The annual examinations are scheduled at different periods of an year for various residents. The data in Table 12 is exclusive of routine annual checkups. The variety of medications prescribed for the residents are given at Appendix A. The trade name, generic name and action of the preparations are listed from the Compendium of pharmaceuticals and specialities of Canadian Pharmaceutical Association (1992). Different trade names were used for some of the preparations which had the same ingredient. The types of drugs used were predominantly anticonvulsants, laxatives, gastrointestinal motility modifiers, antacids, and dermatological preparations.

Summary

Information on medical needs of 36 persons (M: 16, F: 20) were collected in a format made for the purpose. The majority of the persons were aged 21 and above. The majority (22) of the sample had lived at the centre for about 22 years. Birth anoxia and 'unknown' were the most common etiological categories listed. On average during the past three years, there was one medical condition per person needing either hospitalization, referral for specialist examination or investigation, or daily attention by a physician. Seizures, gastrointestinal problems (peptic ulcer or reflux esophagitis, gastric tube insertion), respiratory problems (respiratory distress, aspiration, upper

respiratory infections), fractures, falls, and urinary infections were medical concerns. The diagnosis of seizure was present in 34 clients. Six of the clients were free from convulsions. Skin care, attention to gastrostomy site, feeding with special diet, bronchodilator nebulization, attention to aspiration and chocking, menstrual cramps, wheelchair use and care in moving the residents were the major health care problems needing nursing care. The roles of different staff in performing different health care procedure are listed. Twenty-two persons had maladaptive behavior. Anticonvulsants, dermatological preparations, antipsychotic drugs, gastric motility enhancers, antacids, and bronchodilators were the major categories of drugs used. Most of the clients had prescription for laxatives and all the residents had vitamin supplementation. All the clients had annual medical examinations. Thirteen clients had more than 16 entries for consultation for specific medical problems from 1988 to the middle of 1994. The range of drugs listed in the client files were tabulated.

Chapter 5

Discussion

With the deinstitutionalization process picking up momentum during the past 10-15 years, the majority of persons with mental retardation currently reside with their families or in a variety of community-based residences (Criscicone, Kastner, O'Brien, & Nathanson, 1994). For decades, people with severe mental retardation were cared for in institutional settings due to a belief that they needed constant nursing care. The report by Jacobson and Janicki (1985) on the functional characteristics of 22,256 persons with severe mental retardation in the state of New York runs contrary to this belief. These researchers found that institutionalized cohorts were not markedly disabled when compared to non-institutionalized cohorts. Profiles of individuals with severe disabilities also show that more adults than children are cared for in institutional settings. This observation shows that with growing public awareness and contemporary policies, more children with disabilities tend to remain in their communities. Hence, time has come for those put in institutions 20 years ago to return back to their communities. However, since persons with severe disabilities have more health and nursing care concerns than people in the community (Eyman, Borthwick, & Miller, 1981), it is necessary to assess their health care needs before they are moved into the community. The assessment of health care will help in mobilizing community resources to provide appropriate services to persons moved into

the community. Community placement would thus help in increasing the quality of life of individuals with severe disabilities (Bradley, 1988).

In the present study, it was found that the method of recording the seizures as grand mal, grand mal series, petit mal, and petit mal series was not in keeping with the current international classification of seizures. In addition, it was recorded that every individual had both grand mal and petit mal attacks which is not consistent with the nature of epilepsy (Aicardi, 1994). The procedure of recording seizures, in fact, appeared to be an error on the part of the staff members at the center. This error can be explained in many ways. First of all, the persons witnessing the seizures were predominantly nurse aides or parents. With their background, they cannot be expected to give a diagnosis for the episode. They have to classify an episode according to the categories listed on the chart based on the duration and intensity. Moreover, the nursing staff, as well as the aides have not had refresher courses or continuing education courses to update their knowledge. One possible solution for this is for observers not to give a diagnostic category to the seizure, but to merely describe and record exactly what happened to the client and the duration of the episode. In persons with more than 100 seizures per year, it may be impossible to describe each and every seizure fully. In such instances, the types of seizures a given client manifested could be described in detail at the beginning of the seizure record followed by the frequency and duration of the subsequent spells. Any change in the nature of seizure could then be recorded in detail, when necessary.

The research proposal was cleared by the ethics committees at two places, at the Department of Educational Psychology of the University of Alberta and the provincial family and social services. In order to maintain confidentiality of the parents, all the letters were mailed by the facility. Of the 64 parents and guardians, only 36 (56.25%) consented to have the records of their wards accessed. In a study on health care concerns among parents of children with mental retardation, which required the parents to return a filled up questionnaire, Chomicki and Wilgosh (1992) obtained a overall response rate of 51%. Follow-up phone calls were made by them wherever possible. In the present study, the overall response rate of 56% was obtained after a follow up letter was mailed.

The sample characteristics showed that there were more females than males. This could be due to chance, with a large number of parents of female clients consenting to have the records reviewed. The majority of the sample were adults. Thirty-one (86.1%) were aged 21 years and above. As mentioned earlier, the majority of the sample were transferred from a larger facility to the present one about 20 years ago. In their study on client characteristics and residential placement of persons with mental retardation, Borthwick, Eyman, and White (1987), found that the average age of persons living with families was 18 years while it was 30 years with those placed out of home. The average age of the clients in this study was 31.3 years and the average duration of their stay at the present facility was 17.7 years.

As many of the clients were admitted more than 20 years ago, their records do not contain adequate descriptions of the measures taken to find the etiology. Many of the records describe the condition as cerebral palsy and quadriplegia. In many instances the diagnoses were a carry forward from the previous facility. Some files contained a brief note on the type of delivery and where the client was admitted as a child. Hence, in a large number of records the etiology was unknown (33.3%). The diagnosis of birth hypoxia seemed to be based on the clinical history. MacFaul (1986) reported that in the absence of Down syndrome, an etiological diagnosis may be established in a child with severe mental handicap only in about half the number of cases. There was no diagnosis of Down syndrome in the present sample. In some of the clients, a probable etiological diagnosis was given by a specialist medical person when the client was referred for some other emergency. It may be rightly argued that arriving at an accurate diagnosis at this stage may not make much difference in client management.

An analysis of the major medical problems needing constant medical attention or hospitalization during the past three years showed that four clients did not have any significant problems. Problems requiring medical attention and hospitalization were seizures, intestinal obstruction, admission for endoscopy, fixing a gastrostomy tube, aspiration pneumonia, fractures, urinary problems and so on. In ten individuals four or more of such instances were recorded. On the average, there were 2.7 problems per individual over a period of three years. This is less than one problem per client per year.

Details of health care needs and practices are given in Tables 5 through 8 from different perspectives. Seizures comprise the most common medical problem in persons with severe mental retardation. Jacobson and Janicki (1985) reported a prevalence ranging from 14% to 39% in this population. The prevalence increased with severity of retardation. Persons staying in an institutional setting tended to have more seizures than do those in the community. Presence of seizures could have prevented placement in the community because of the perception of a greater need for supervision of clients with recurrent seizures. In the present sample 34 (94.4%) had a diagnosis of seizures in their files while 28 (77.9%) had seizures in the last year. This figure is very high compared to that reported in the literature. The fact that the sample size is small and the group may not be totally representative of the population of severe disabilities has to be kept in mind before drawing further conclusions from this figure. Status epilepticus was noticed in three instances during the past three years. Persons with severe mental retardation and seizures may have troublesome behavior problems. Problem behavior may be due to the associated brain damage or a consequence of an overenthusiastic anticonvulsant medication (O'Donohoe, 1994). Some anticonvulsant medications may produce severe giddiness as a side effect, the client's reaction to which might be interpreted as a problem behavior. In the present sample, of the 28 persons who had seizures, 14 had problem behaviors, while of the eight who did not have seizures, five had problem behaviors. There seemed to be no correlation between problem behavior and the

presence of seizures in the present sample. From the files, one cannot make an assessment of the intensity and frequency of the behavior problems. As mentioned earlier, all categories of seizures were counted as one variety and the total number was added for each year. The seizure frequency was calculated from the number of seizures during the preceding two years. The majority had less than 20 seizures per year.

Entries about gastrointestinal problems were found in 23 instances. Some persons had more than one entry. Ten clients had gastrostomy tubes. Five had a diagnosis of hiatus hernia and one had an inguinal hernia. In a survey of 220 residents of a developmental centre, Rogers, Stratton, Victor, Kennedy, and Andes (1992), observed that 10.4% had chronic regurgitation. On further investigation, 22 of them were found to have gastroesophageal abnormalities. In the present study, 14 (38.8%) had combinations of gastrointestinal problems; ten of these individuals had peg tube insertions. The number of gastrointestinal disorders in the present study are higher than those reported in the literature (Kuruvilla & Trewby, 1989; Rogers et al., 1992).

Of the gastrointestinal problems, intestinal obstruction could end fatally in persons with mental handicap because of atypical presentation. In a retrospective study of hospital records over a 50 year period, Jancar and Speller (1994), observed a higher incidence and a lower mean age at death due to fatal intestinal obstruction in persons with mental handicap. Chronic constipation and megacolon were present in the subjects. Vomiting and

abdominal distension were absent and the period of acute illness was short. Correct diagnosis was made in the study of Jancar and Speller only in 8 of the 32 persons who had fatal intestinal obstruction. In the present study, intestinal obstruction due to volvulus was recorded for one individual. Roy and Simon (1987) observed that intestinal obstruction presented with minimal symptoms in persons with mental handicap.

An examination of the pattern of diet given to the clients showed that only one client had a regular diet. Twenty-one had minced diets, seven pureed, and ten were on gastric tube feeding. Two were occasionally on nasogastric feeding, during conditions like status epilepticus. The type of minced diet was categorized as large or medium. All the clients needed assistance to eat. In a study of 111 persons with severe and multiple handicaps, Ohwaki and Zingarelli (1988), reported that 53.2% were on tube feeding, 20.7% on minced diet and 26.1 on regular diet. Feeding was a major area that required skilled nursing and it consumed up to 38% of the working time of the nursing staff.

Respiratory problems formed the next major concern. These were either aspiration, choking, and pneumonia or bronchial asthma. Three persons (8.3%) had a record of aspiration pneumonia. Five (13.8%) had a tendency to aspirate and choke while six (16.6%) persons had respiratory distress during the past three years. Prevalence of respiratory problems in persons with mental retardation ranged from 1.5% to 7% in a review of five studies by Day and Jancar (1994). Ten of the residents (27.7%) were reported to

have suffered from intermittent wheeze and were on regular nebulization with broncho dilator medications. However, a frank diagnosis of bronchial asthma was present in only four files (11.1%). Bronchial asthma is increasingly recognized as a health problem in persons with disabilities. There are still controversies as to the proper diagnosis of the condition (Nolan, 1994). On observation of even minimal wheeze, bronchodilator nebulization has been found to offer good relief.

Falls and fractures are reported at a higher prevalence in persons with disabilities, especially in those in institutional settings (Dunne, Asher, & Rivara, 1993). Osteoporosis, seizures, use of psychotropic drugs, falls, use of long term thyroid preparations, and lack of exercise leading to reduced muscle mass are reported to predispose persons with severe disabilities to fractures. In many instances, the causes of the fractures are not known (Jancar, 1989). In the present sample, fractures were recorded in eight instances. One person had repeated fractures of both bones of a leg. Most of the individuals in the present study were quadriplegic. In view of the prolonged lack of use of limbs and the client's ages, it is probable they had developed osteoporotic changes leading to brittle bones. Because of lack of mobility, the prevalence of skin breakdown in the subjects is fairly high which necessitates frequent changes in position.

Of the genito-urinary problems, urinary tract infections were frequent. Of the gynecological problems, menstrual cramps were reported for nine

clients. Huovinen (1993) reported that less number of women with mental retardation had gynecological problems than women with normal intelligence. A large number of women with mental retardation in Huovinen's study were prescribed progesterone preparation to induce amenorrhea. In the present sample two prescribed oral contraceptives for dysmenorrhoea.

Individuals with severe and profound mental retardation have biological deficits resulting in developmental delays. Systemic changes, as well as environmental interactions affect the individuals and bring about various behavior problems (Bishop, 1992). In the present sample, 19 persons had behavior problems. However, only eleven were on antipsychotic or hypnotic medication, which is a good sign. Thirteen persons exhibited self-injurious behavior. However, self-injurious behaviors were not persistent in many. Analysis of problem behavior and suggestions for management were present in some records. However, the details on implementation were not available.

The medical prescriptions of all the residents were analysed to identify the range of medications used. All of the residents were given vitamin supplementation. Problems in gastrointestinal motility necessitated the use of laxatives and gastric motility drugs. Most (97.2%) had a prescription for a laxative or a stool softener. About 21 were on a bowel routine for chronic constipation. Gastric motility drugs like methoclopramide were used to enhance gastric emptying, thereby preventing stasis of food in stomach with

secondary complications. Lack of physical activity could have resulted in these problems.

Anticonvulsants, dermatological preparations, antipsychotics, and analgesics were the other drugs used frequently. In a survey of 15 community centered boards catering to 1282 persons with mental retardation, Zaharia and Struxness (1991) noted that antipsychotic drugs were used in 18.6%, while anticonvulsants were used in 21.8%. Combined use was found in 34.6% instances. Rubin (1987) reported that 81% of children with mental handicap in a hospital setting received medications; anti-convulsants formed 34%, and antipsychotics 24%. The use of medications was higher in the subjects of this study. As 34 persons had a diagnosis of seizures, the use of anticonvulsants was inevitable. The antipsychotic medications were used in low doses and this was not perceived as a problem. The use of dermatological preparations were necessitated because of gastrostomy tubes in ten persons as well as presence of skin breakdown problems. In a study by Searle, Berelowitz and Wright (1989) the use of anticonvulsants and dermatological preparations increased with increasing severity of mental retardation. Analysis of the seizure medication showed that 21 persons received two or more anticonvulsant preparations. A shift from polyphramacy (use of more than one drug) to monotherapy in anticonvulsant drug prescription is the current trend (O'Donohoe, 1994). Use of sodium valproate and carbamazepine as first line of medications in persons with mental retardation instead of phenobarbital and dilantin has been

recommended because of frequency of side-effects with the latter drugs (Schain, 1979).

Based on the review of literature, twenty four health related needs were identified and entered in the data collection sheet. Of these, eleven procedures were not required in the present sample. They were; cardiopulmonary resuscitation, shunt care, prosthesis care, cast care, use of nasal cannula, oxygen supplementation, bulb syringe suction, use of oxygen mask, mechanical ventilation, change of tracheostomy tubes/ties, and colostomy/ileostomy care. Thus the clients in the present group have less number of health care needs than are generally expected in this group of population.

Entries in the medical record give an index of the frequency of medical consultation. Doctors entries since 1988 were counted in each file. Only thirteen clients had more than 16 entries over a period of six-and-a-half years. The total number of doctor entries apart from the routine annual checkups were 522. This works out to 2.2 consultations per client per year. On an average, a person living in Alberta required 0.92 visits to a physician during the year 1992-93 (Alberta Health, 1993). Howells (1986) observed that, for a person with mental handicap, four consultations with a general practitioner per year was adequate . In Howells's study, it was reported that, persons with mental retardation living in hostels or lodgings had adequate physician consultations than those living at home. In the present facility easier access to doctor's consultation was available than in a community.

However, residents needed less than three doctor contacts per year. The clients were in need of help by a nurse or a nurse aide, than a physician, on a regular basis for their routine health care needs. Except for specialized procedures like gastrostomy feeding, medication administration, and catheterization, the clients could manage with the help of a nurse-aide. Hence, with appropriate preparation of support staff, the clients in this centre could be moved to a community setting. Physician visits which may average three per year can be met by a community practitioner.

While the data were collected from the files, it was observed that some of the files contained consents from the parents and guardians for a do not resuscitate (D. N. R.) order to be written for their ward by the attending physician. It was later learned that the physician had written to the parents of each of the residents requesting them to consent in advance for a D. N. R. in the event of some catastrophe happening to the residents. Of the thirty six, 28 (77.7%) consented for the physician to write an advance D. N. R. order for their wards and the charts for these clients were labelled 'Do Not Resuscitate'. As it was seen earlier, persons in this center, on average, did not require more than three physician contacts per year.

D. N. R. orders which were first described in 1976 (Rabkin, Gillerman, & Rice, 1976), are orders written to proscribe the use of cardiopulmonary resuscitation in the event of a cardiac arrest. In a chart review of D. N. R. orders in a children's hospital over a one year term, Lantos, Berger, and

Zucker (1993) observed that most of the D. N. R. orders were written for patients who were receiving aggressive medical therapy in the intensive care unit. Clients in this facility did not exhibit chronic emergency critical care condition as would be found in intensive care units. Their frequency of physician contacts were similar to any other normal person. However, anticipating a critical care situation for the clients, the guardians consented for a D. N. R. well in advance. This poses questions about the basic role of the guardian. Commenting on the limits of the guardian decision making in case of a 'person with severe mental retardation and other never competent persons', Veatch (1986) commented that as persons with severe mental retardation are not competent to make their own treatment choices, the guardian should act in such a way that the patient's best interests are served. The guardian should also know the limits of his/her decision-making on behalf of the person with severe mental retardation.

Guardians can differ in their interpretation of the best interests of their wards and, invariably there is lot of subjectivity in the term 'best interests'. Some people might consider that not treating persons with severe disabilities and "letting them die" is a legitimate form of medical intervention. Many rationalizations such as "these individuals are not really people" and the individuals lack quality of life, can be convincingly put forward by a group of people to the extent of advocating euthanasia for people with severe handicaps. Lusthaus (1985) cautioned parents and professionals to refute such rationales. Matthews, Meier, and Bartholome (1990), commenting on the

ethical issues in pediatric rehabilitation noted that 'best interests of the child' should result in child-centered decisions, that is, the decisions should have the child's life as the top priority than other considerations like excessive costs. Resource allocation is of special concern in disabled children since they may consume significant resources in medical and rehabilitation costs spent throughout a lifetime. These costs may be justifiable when a disabled child matures into a productive adult. In the present facility, in the absence of any emergency situations, asking and consenting for a D. N. R. seem unwarranted since most of the residents lived through to adult life without any critical care situation.

With the available information on the needs of the clients in this facility, an attempt was made to construct a broad profile of an individual residing in this facility. Generally a client has quadriplegia, needing a wheel chair for mobility, and the aid of staff for transport. There is a 77% chance of having seizures; 63% chance of having reflux, or a feeding problem; the individual is totally dependent on others for feeding needs; has a special diet, either minced or pureed, has a 27% chance of having a gastrostomy tube in place; has 2-4 laxatives or stool softeners prescribed, in the event of chronic constipation, has a bowel routine in place; is at risk for aspiration and choking, sometimes (27%) needs nebulization for wheeze; is at risk for fracture and skin sloughing; has occasional problem behavior. The client has a need to contact a physician for specific illness 2.2 times a year. Thus, while

the need for physician contact is less than three per year, there is a need for a trained person, to be around to care of the client's needs. Persons who took care of clients at this centre need to be oriented and trained in: seizure recognition and management, administration of prescribed medication, feeding either a special diet or through a gastrostomy, bowel care, preventive management of aspiration and choking, use of nebulizer, appropriate procedures to lift the person and wheelchair use, and prevention of skin break down (attention to frequent change in position) and fractures. Hence, when a move is made to place the clients in the community, persons trained in the above skills should be recruited as managers of the community homes.

Chapter 6

Conclusions

The present research attempted to identify the specific health care needs of a group of residents in a residential facility of persons with severe disabilities from their medical records. The majority of persons were adults with severe and multiple disabilities. Etiology was not known in one third of the sample. The major etiological diagnostic category was birth anoxia/ hypoxia. On the average, each resident had 2.7 medical problem needing daily, medical attendance/hospitalization during the past three years.

The major health care problems were seizures. The percentage of clients who continued to have seizures was 77.7%. Status epilepticus was recorded in 8.3% of case records. Gastro-intestinal problems were present in 63.8% with the major concerns being reflux esophagitis and gastrostomy tube insertions. Chronic constipation was a problem, needing regular use of stool softeners and laxatives. All clients except one needed special diet. All clients were dependent on staff for their feeding needs. Aspiration and choking were the major concerns of the respiratory system. Recurrent wheezing, needing nebulization, was present in 27.7%. Upper respiratory infections were present with the same frequency as is found among the normal population.

Fractures and dislocations contributed to 27.7% of health care concerns. The nature of the disability in the clients seemed to predispose them to easy fractures. All the subjects were non-ambulatory and needed wheelchair use.

Non-ambulation seemed to predispose the clients to recurrent skin sloughing needing constant skin care. As a result the number of dermatological prescriptions were high. The genito-urinary concerns included urinary tract infections and menstrual cramps. Problem behavior was recorded in 52.7% of records. However, the problem seemed intermittent and many clients were not on high dose psychotropic medication. Analysis of medication prescription revealed frequent use of anticonvulsants, dermatological preparations, anti-psychotic drugs, gastrointestinal motility enhancers, and analgesics.

Need for physician contact for specific illness was assessed based on the number of entries in the doctors' notes. It was found to be 2.2 consultations per client per year which is slightly more than twice the number required by non- disabled person. This number is an encouraging factor for placing the clients in the community. The nursing needs should be considered carefully before such a move is undertaken.

Two concerns arose while reviewing the case records. One was the classification of the seizure patterns which needed to be revised. The second was the Do Not Resuscitate order in the client files. Both concerns were conveyed to the authorities of the facility.

Limitations of the Study:

The data was collected from the medical records of the residents. The focus was on a broad area of all the health care needs and not on a specific issue like mode of prescription of medications or frequency of occurrence of a particular condition. Because of a broad focus of enquiry there was a chance

of overlooking some conditions as well as duplicating the same entry. In order to avoid this error, only three records were reviewed per day, and at least three hours were spent in gathering data from each file. The actual time spent by support staff on each health care procedure is not mentioned in the records and can only be obtained by detailed observation of the procedures. Moreover, a particular procedure can take varied amount of time based on the physical condition of the person. For example, residents may differ in the amount of time taken to have the feed based on the condition of their swallowing mechanism, presence of dysphagia, thoracic abnormalities, reflux and so on. Oral feeding may consume more staff time where as a gastrostomy tube when used may take less time, but requires more skill. Similarly presence of seizures, and problem behavior make the specific health care needs unique to an individual. Hence one can obtain only broad inferences from this type of a study.

While inferences like the average physician contacts, number of medication needs, number of needed health related procedures can all help in planning the community living for the group as a whole, clients may have to be assessed on an individual basis before a decision is taken to place them in the community. Except for clarifications on the records, no direct staff interviews were conducted in this study. Such an interview could have thrown light on the problems encountered if any, in carrying out various health related procedures, and what the staff perceive about the feasibility of carrying out the procedures in the community.

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Appendix A

Drugs used with the clients. (Trade name, Generic name and drug action)

Name of the Drug	Action
Alphalac (lactulose)	Laxative
Agarol	Mineral oil-glycerin phenolphthalein (laxative)
Atrovent (ipratropium bromide)	Bronchodilator
Bisacodyl	Laxative
Cortate (hydrocortisone)	Topical corticosteroid
Depakene (valproic acid)	Anticonvulsant
Dilantin (phenytoin)	Anticonvulsant
Docusate sodium (taro)	Stool softener
Ensure	Enteral feeding
Fleet enema (sodium phosphate)	Laxative
Frisium (clobazam)	Anticonvulsant
Frosst 222	Acetaminophen-analgesic, antipyretic
Gavison (algenic acid compound)	Gastroesophageal reflux therapy
Isocal	Therapeutic nutrient
Jevity	Therapeutic nutrient
Lactulose	Laxative (hyperosmotic)
Losec (omeprazole)	H, K ATPase inhibitor-antacid
Maxeran (metoclopramide Hcl)	Upper G. I. tract motility modifier, antiemetic
Maalox (mag-aluminium hydroxide)	Antacid
Novoneprox (naproxen)	Analgesic anti inflammatory agent
Novotetra	Tetracycline Hcl antibiotic
Novoperidol (haloperidol)	Antipsychotic

Appendix A (contd.): Drugs used with the clients

Name of the Drug	Action
Nozinan (methotrimeprazine)	Antipsychotic
Ovral 28 (norgestrel-ethinyl estradiol)	Oral contraceptive
Pardec liquid	Vitamin
Pedialyte	Oral electrolyte maintenance solution
Phazyme (semithiocone)	Antiflatulent
Phenobarbital (barbiturate)	Anticonvulsant-hypnotic
Ponstan (mefanamic acid)	Analgesic
Prepulsid (cisapride monohydrate)	Gastrokinetic drug-antireflux drug
Pulmicort (budesonide)	Glucocorticosteroid, asthma therapy
Reglan (metoclopramide Hcl)	Upper G. I. tract motility modifier - antiemetic
Restoril (temazepam)	Hypnotic
Salbutamol	Bronchodilator
Senocot (stand. senna concentrate)	Peristaltic stimulant
Sulcrate (sucralfate)	Gastroduodenal cytoprotective agent
Tegretol (carbamazepine)	Anticonvulsant
Tylenol (acetaminophen)	Analgesic, antipyretic
Uripas (flavoxate hydrochloride)	Urinary tract antispasmodic
Ventolin (salbutamol)	Bronchodilator
Zilactin (tannic acid)	Protectant - cold sore therapy

Appendix B

University of Alberta
Department of Educational Psychology
Severe Disabilities Program

Health Care needs of Persons with Severe Disabilities

CONSENT FORM

I understand that under the Severe Disabilities Program of the Department of Educational Psychology, University of Alberta, a research project 'Health Care Needs of Persons with Severe Disabilities' is proposed. I further understand that the research work would be done at a facility in western Canada* and the medical records of the residents would be used for the study. I also understand the following items:

(a) that the information in the medical records would be used for gathering health status profiles of the residents,

(b) that the names of the individuals will be kept confidential,

(c) that the parent or the guardian has the right to revoke consent and withdraw from participation at any time,

(d) that the records would be examined at the facility alone, and

(e) that no fee would be charged for the data analysis, nor would the parents/guardians be paid any money for using the records.

I have read the attached description of the study and I understand the nature of the study. I hereby give consent to the release of the medical records of my ward Mr/Ms

_____

a resident of the facility to Dr. Dick Sobsey and Dr. Madhavan Thuppal of the Severe Disabilities program of the University of Alberta.

Parent's or Guardian's signature Date Signature of witness Date

*the name of the facility is not mentioned here in order to maintain confidentiality of center.

Appendix C

University of Alberta

Faculty of Education
Department of Educational Psychology
Severe Disabilities Program

Health Care needs of Persons with Severe Disabilities

DATA COLLECTION SHEET

1. Name: 2. Date of birth & age: 3. Gender: M/F

4. Duration of stay: yrs. months.
(total institutional placement)

5. Significant history if any:

6. Details of medical examination & medical reports:
(Include details on any of the emergency procedures carried out during the past 2-3 years)

7. Diagnosis:

-Type of disability

-Cognitive level

-Etiology of disability

-Medical problems:

a.

b.

Medications being given:

1.	2.
3.	4.
5.	6.
7.	8.
9.	10.
11.	12.

Health related procedures needed by the person:

	Yes/No	By whom*	Frequency
1. Seizure monitoring and emergency seizure procedure. Type of seizure Frequency Duration Any emergency hosp admn.			
2. Teeth and gum care (daily & dental care)			
3. Prevention and treatment of skin breakdown			

	Yes/No	By whom*	Frequency
4. Gastrostomy feeding			
5. Establishing bowel habits			
6. Diet monitoring and supplementation			
7. Care of respiratory system			
-Postural drainage			
-Suctioning			
-Chest physiotherapy			
(List ventilation problems or aspiration pneumonia if any)			
8. Handling and positioning			
- Physical disability			
- Type of aid needed			
- Fractures and dislocations			
9. CPR			
10. Medication administration			
Prescription Medication			
Medication on PRN			
11. Shunt care			

	Yes/No	By whom*	Frequency
12. Prosthesis care (leg, arms, eyes)			
13. Cast care			
14. NG tube feeding			
15. Administration of enema			
16. Catheterization procedures			
17. Nasal cannula			
18. Oxygen supplementation (Humidified air)			
19. Bulb syringe suction			
20. Oxygen mask			
21. Mechanical ventilation			
22. Changing tracheostomy tubes/ties`			
23. Colostomy/ Ileostomy care			
24. Gynecological problems			
25. Behavior			
Aggressive			
Withdrawn			
SIB			
25. Any other			

*Nurse, Nurse aid, Paramedic, Special tea[illegible] other

Appendix D

Glossary of terms used

Acne: inflammation of the sebaceous glands of the skin producing small eruption of the skin. Generally this is observed over the face, upper back and chest.

Analgesic: a compound which relieves pain.

Antacid: an agent that neutralizes acidity of the gastric juice.

Anticonvulsant: an agent which prevents or arrests convulsions.

Antiemetic: a remedy that tends to control nausea and vomiting.

Antiflatulent: an agent that tends to reduce the amount of gas in the intestines.

Antipsychotic: an agent that tends to reduce psychotic symptoms.

Antipyretic: an agent that reduces fever.

Antispasmodic: an agent that reduces spasm of smooth muscles (of gastro-intestinal tract, or uro-genital tract).

Asphyxia: impaired exchange of oxygen and carbon dioxide across the lungs.

Aspiration (Choking): the inspiratory sucking into the respiratory system of fluid or foreign body, as of vomitus.

Bartholinitis: inflammation of Bartholin's gland (a vulvo vaginal gland).

Birth hypoxia: decreased amount of oxygen in the blood vessels at birth. This can arise due to various reasons - decreased inspiration, constriction of a blood vessel and so on. Birth hypoxia if present for more than five to ten minutes can potentially damage the nerve cells in brain.

Bronchial asthma: condition of lungs in which there is widespread narrowing of airways. The duration of contraction is variable. There is excessive secretion of mucus and the mucus membrane becomes edematous.

Bronchodilator: an agent which causes an increase in the caliber of a bronchus or bronchial tube.

Callous: a circumscribed thickening of the keratin layer of the epidermis as a result of friction or intermittent pressure.

Cardio Pulmonary Resuscitation: C. P. R. - restoration of cardiac output and pulmonary ventilation following cardiac arrest and respiratory arrest using artificial respiration and closed chest massage.

Caries: destruction or necrosis of teeth.

Complex Partial Seizures: C. P. S. Type of seizures which start at a particular focus in the brain and spread in a diffuse way. If the intensity of the electrical activity is more, the seizures become generalized.

Cramps: a painful spasm of muscles.

Cyanosis: a dark bluish or purplish coloration of skin and mucous membrane due to deficient oxygenation of blood.

Dermatitis: inflammation of the skin.

D. N. R. : Do Not Resuscitate - order written by the doctor on the file of a terminally ill patient in order to refrain from doing a cardiopulmonay resuscitation or employ extra-ordinary procedures to prolong life. This order is written at the request of the patient or his/her guardian.

Dysmenorrhoea: difficult and painful menstruation.

Dystonia: a state of abnormal tonicity in any of the tissues.

E. E. G. : Electroencephalogram. A record of electrical potentials of brain derived from electrodes attached to the scalp.

Emesis: vomiting.
Encephalitis: Inflammation of the brain.
Endoscopy: examination of the interior of a canal or a hollow viscus by means of a special instrument such as an endoscope.
Enema: a rectal injection for cleaning out the bowel, or administering drugs or food.
Epistaxis: to bleed at the nose.
Gastrokinetic: an agent which increases gastric mobility.
Gastrostomy tube: establishment of a new opening into the stomach.
Gastro-intestinal bleeding: bleeding relating to stomach and intestines.
Gastro-intestinal motility modifier: an agent which increases the frequency of contraction of muscles of stomach and intestines.
Grandmal epilepsy: a generalized epilepsy of tonic-clonic pattern.
Hemolytic disease of the newborn: condition in a new born characterized by breakdown of red blood cells due to incompatible blood groups of fetus and mother.
Hernia: protrusion of a part or a structure through the tissues normally containing it.
Hiatus hernia: protrusion of the stomach through the esophageal hiatus of the diaphragm
Humerus: bone of the arm articulating with the shoulder bone.
Hydrocele: collection of serous fluid in a sacculated cavity, specifically around testis.
Hydrocephalus: a condition of excessive accumulation of fluid in the cavities in brain leading to thinning of brain tissues and marked enlargement of the head.
Hyperosmotic: having increased osmotic or fluid pressure due to increased concentration of substances in the fluid.
Hypoplastic lung: underdeveloped lung.
Jacksonian epilepsy: a convulsive attack beginning with twitching of the peripheral part of a limb extending to involve the proximal muscles; may spread to entire side and become generalized.
Kyphosis: hump back; a deformity of the spine characterized by extensive flexion.
Laryngeal stridor: high pitched noisy respiration due to obstruction in the larynx. Obstruction in the larynx is generally congenital.
Laxative: mild cathartic; a remedy that has the action of loosening the bowels.
Meningitis: inflammation of the covering around the brain or the spinal cord.
Minced diet: regular food broken into small pieces so that it does not require too much chewing.
Nasogastric tube: a tube inserted up to the stomach, through the nose. The tube can be used to aspirate the contents of the stomach, or inject food directly into the stomach.
Nebulization: spraying or vaporization, medication administered as a spray especially to deeper parts of the respiratory tract.
Orchiectomy: removal of one or both testes.
Osteoporosis: reduction in the quantity of the bone, resulting in bone trabeculae that are scanty and thin; generally occurs in old age, or due to prolonged immobilization.
Peptic ulcer: ulcer in the stomach.
Petit mal epilepsy: absence seizures; characterized by staring spells
Peritonitis: Inflammation of peritoneum, the membrane covering the abdominal cavity.
Pneumonia: Inflammation of the lung tissue.
Postural drainage: drainage of fluid especially from lungs by the effect of gravity and the position of the body.
Prematurity: occurring before the expected time; infant born after less than 37 weeks of gestation.
P. R. N.: abbreviation for a latin word 'pro re nata', as the occasion arises.

Prosthesis: fabricated substitute for a diseased or missing part of the body.
Psychotropic: affecting the mind, used to denote the drugs used in the treatment of mental illnesses.
Pureed diet: diet broken into a soft liquid form.
Reflux: a backward flow; esophageal reflux , regurgitation of contents of the stomach into the oesophagus.
Regurgitation: backward flow; to expel contents of the stomach in small amounts; short vomiting.
Respiratory distress: a distress relating to difficulty in respiration.
Rubella: german measles; a viral infection. If a pregnant women is infected with this virus, there is a high probability of the fetus developing congenital abnormalities.
Scaling: removal of accretions from the crowns and roots of teeth by use of special instruments.
Schilder's disease: adrenoleukodystrophy; a degenerative disease involving the white matter of the nervous system and the adrenal glands.
Seizure: convulsions, an epileptic attack.
Sepsis: presence of various pus forming organisms, or their toxins in the blood or tissues.
Sequestrated liver: a piece of liver separated from the main mass of tissue.
Status epilepticus: a condition of repeated seizure; a seizure prolonged for at least 30 minutes; may be convulsive, non-convulsive or partial.
Stomatitis: inflammation of the mucous membrane of the mouth.
Suppository: a small solid body shaped for ready introduction into one of the orifices of the body other than the oral cavity (e.g., rectum, urethra, vagina), usually medicated, solid at room temperature but melts at body temperature.
Tartar: a white, brown, or yellow brown deposit at or below the gingival margin of the teeth.
Topical corticosteroid: local steroid preparation; a skin cream containing steroids.
Tuberous Sclerosis: a condition characterized by adenoma sebaceum (small tumor like masses over the cheek bones), mental retardation, and seizures.
U. R. I. : Upper respiratory tract infection.
U. T. I. : Urinary tract infection.
Volvulus: a twisting of the intestine causing obstruction.

Appendix E

Correspondence

22 April 1994.

Dear Parent or Guardian:

We are writing to you to request access to the medical records of your family member or ward who resides at the facility for research purposes. We have asked the staff of the facility to mail this letter to you to maintain the privacy of anyone who chooses not to consent. This letter describes the research. First, we would like to introduce ourselves.

Dr. Madhavan Thuppal is a physician who specializes in health care needs of people with developmental disabilities. He is currently doing post graduate studies at the University of Alberta. Dr. Dick Sobsey is a Professor of Educational Psychology at the University of Alberta. He is a registered nurse and certified teacher. He has worked with people with developmental disabilities for more than 25 years in residential and community settings. Both researchers are interested in the health care needs of people with developmental disabilities.

The purpose of this study is to review, identify common and infrequent health care needs of people with developmental disabilities over extended periods of time. This information will be useful in guiding health care providers. Confidentiality will be strictly maintained. Data will be gathered from medical records at the facility and discussing these records with health care providers at the center. No direct examination will take place and participants will not be subjected to any experimental treatment. Confidentiality will be strictly maintained. Data will be coded before it is removed from the centre so that no names will be identifiable.

This research has potential benefits for individuals who participate. A full review of each participants medical record will be completed. This review may suggest some health care intervention that could be of benefit to the individual's attending physician for evaluation. The results of previous studies suggest that such reviews often identify health care information that is of practical benefit to participants.

We request your consent to access these records. It will help us with our research and it has potential to benefit each participant with very little risk since only the participants' records are involved. Nevertheless, the decision to consent or to withhold consent is entirely up to you. If you do consent, you have the right to withdraw that consent at any time. If you give your consent, please fill out the enclosed form and return it in the stamped, self-addressed envelope that we have provided, before May 12, 1994. If you have any questions, would like additional information or want to discuss any aspect of this research, please feel free to call Dr. Madhavan at 492-1142 or Dr. Sobsey at 492-3755.

Thank you for considering this request.

Sincerely,

Madhavan Thuppal, MD

Dick Sobsey, EdD

16 June 1994

Dear Parent or Guardian,

We wrote to you in April requesting access to the medical records of your child or ward who resides at the facility for research purposes. The staff of the facility mailed you the letter along with the consent form and self addressed envelope. We are pleased to receive consent forms from a number of parents/guardians and we have started the actual process of data collection. However, we would be pleased to include the data from the records of your family member/ward as well so that we have information from as many records as possible. We are enclosing our original letter of 22 April and a copy of the consent form in case you misplaced the letter and the consent form. We hope you will find it appropriate to consent to permit us to access the medical records of your family member/ward for the research project.

We are enclosing another self addressed envelop in order to make it convenient for you to mail it to us. If you have any questions, please feel free to call Dr. Madhavan at 492-1142 or Dr. Sobsey at 492-3755.

Thank you for considering this request.

Sincerely,

Madhavan Thuppal, MD

Dick Sobsey, EdD